

Office of Public Health (OPH) Quarterly Report to the DD Council
Bureau of Family Health (BFH)
March 27, 2018

Children and Youth with Special Health Care Needs (CYSHCN) Programs

Children's Special Health Services (CSHS) works to ensure that children and youth who have special health care needs in Louisiana have access to health care services designed to minimize their disabilities and maximize their probabilities of enjoying independent and self-sufficient lives.

- CSHS continues direct service clinics for CYSHCNs in regions 2 and 4-9 to meet specialty care needs in provider shortage areas. CSHS clinics are staffed by part-time physician sub-specialist, a full-time nurse, and parent liaison. CSHS parent liaisons are the parent of a child/young adult with a special health care need and work in tandem with the clinic staff to assist parents with coordination of care and linkage to community services. In Regions 2, and 6-9, the care team also includes a social worker.
- CSHS supports care coordination (CC) services in 6 academic clinics through partnerships with Children's Hospital New Orleans (CHNOLA), Daughters of Charity, NOELA Community Health Center, Lafayette General Hospital -University Hospital and Clinics, and Tulane Lakeside Pediatrics clinic. This project provides area families access to CC services and allows residents to gain personal experience with the medical home healthcare delivery model.
- CSHS promotes comprehensive developmental screening (DS) in pediatric primary care practices around the state. Providers who serve the birth to five population can participate in free technical assistance (TA) around comprehensive DS and CC. Currently DS TA is available to Region 4 providers and will expand to Region 9 on April 30, 2018. Information on the DS project, DS recommendations for LA providers and free DS resources can be found at www.ldh.la.gov/developmentalscreening.
- CSHS recently concluded the 2018 biennial Statewide Provider Survey. This survey is part of the state's plan to improve the health and well-being of children in Louisiana and designed to help the program learn more about the services provided to the children in our state. The data from this survey will guide future program initiatives supporting Louisiana children and their health care providers. The preliminary participant count for the survey is 183 primary care providers and 73 developmental screening providers. Once data analysis is complete, the survey report will be available on our website at www.ldh.la.gov/cshs.
- CSHS is hosting a Resource Information Workshop (RIW) Thursday, April 26, 2018 from 8:30AM-3PM at the North Oaks Diagnostic Center in the E. Brent Dufreche Conference Center. The RIW *Improving Early Identification and Access to Comprehensive Care for Children and Youth with Special Health Care Needs (CYSHCN)* offers 4 hours of continuing education credit for nurses, social workers and Licensed Professional Counselors. The registration link for the event is www.selariw2018.eventbrite.com.

The CSHS Family Resource Center (FRC) located on the campus of CHNOLA connects Louisiana families with needed resources through outpatient clinics and the inpatient rehabilitation unit. The FRC also links families with their local Families Helping Families center for ongoing support.

The FRC staff attend the following clinics: Botox, Spasticity, Neuromuscular, Spina Bifida, Down Syndrome, Muscular Dystrophy, Cerebral Palsy and Neurology Transition clinic. Beginning in April 2018, the FRC staff will also attend in the new Skeletal Dysplasia clinic.

- The 2018 FRC Resource fair at CHNOLA on *Early Childhood Behavioral Health*, is scheduled for April 13, 2018.
- The FRC parent liaison, Thuy Nguyen, serves on the CHNOLA Commission on Accreditation of Rehabilitation Facilities (CARF) providing the family perspective and resource information to inform the group’s work.
- The FRC youth liaison, Steven Nguyen, participates in the Statewide Independent Living Council and serves in the role of vice chairman; sits on the Developmental Disabilities Council; and is a member of the Jefferson Parish Complete Streets Coalition.

Family Resource Center	
Resource Dissemination Activities December 2017 - February 2018	
Total Client Encounters	218
Identified Resource Needs	509
Resource Needs Met	519

Louisiana Birth Defects Monitoring Network (LBDMN) tracks the occurrence of over 70 structural, functional, and genetic birth defects in Louisiana residents. This work helps to ensure that there are no unknown environmental conditions, pharmaceutical side effects, or behavioral risk factors threatening Louisiana's newborns.

Traditional Case Definition Surveillance:

- The 2014 birth cohort closed at the end of December 2017. Analysis is pending. Note: birth cohorts are closed within 3.5 years due to our case definition of following children up to their third birthday.

Zika Case Definition Surveillance:

- Abstraction continues for potential cases of interest for Zika related birth defects. The 2016 Zika cohort closure has been delayed due to database delays. Expected date is mid-April 2018.
- The Zika surveillance upgrade to the existing database was in January 2018. We are currently working through some glitches with data collection workflows and data extraction/ reporting. These are to be expected when retrofitting an electronic database. This upgrade will greatly enhance efficiency in Zika surveillance.
- All but three (48 of 51) birthing hospitals in the state have submitted revised reports with the Zika codes for 2016-17 discharges.

- We have secured remote access for record abstraction at 33 of 51 reporting facilities that have remote capability and are willing to grant permissions to outside entities.
- It is noteworthy that Louisiana has not had any live births with maternal Zika exposure or Congenital Zika Syndrome to follow for referral, care coordination, health or developmental outcomes.

CSHS Transportation Assistance Program provides needed transportation assistance for families to attend medical appointments/procedures.

Transportation Assistance Program November 2017 - January 2018	
139 families served	Stipend expenditures \$16,626

Genetic Diseases Program operates a comprehensive statewide newborn heel stick screening program meeting national standards as well as ensuring access to genetic evaluation and counseling to residents of Louisiana. It also operates the Sickle Cell Disease (SCD) Program, which provides resources and information on how individuals diagnosed with sickle cell can receive assistance and care through the Sickle Cell Foundations and Clinics around the state.

- The Louisiana Sickle Cell Commission (LSCC) webpage, <http://ldh.la.gov/index.cfm/page/2900>, provides information on the activities of the commission, while highlighting its members, partners, and state SCD resources.
- The Louisiana Sickle Cell Commission (LSCC) will cohost a conference with Ochsner New Orleans on June 8-9 to bring all stakeholders together in the fight against sickle cell disease to achieve better healthcare results.

Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program (LHHCLPPP) works toward the goal of eliminating childhood lead poisoning as a public health problem. During this quarter, the program continued work on initiatives to promote lead poisoning prevention.

- The LHHCLPPP hosted the HUD Deputy Director during a site visit March 26-28, 2018.

Hearing Speech and Vision - Early Hearing Detection and Intervention (EHDI) Program conducts the newborn hearing program in Louisiana (LA). EHDI is a national initiative that supports the early identification of infants with hearing loss through screening, audiologic evaluation, medical evaluation, enrollment in early intervention, and family to family support services.

- The EHDI Program is collaborating with the Deaf/Blind Project to host a conference at LSU-HSC in New Orleans in September 2018.

- The EHDI Program is working to engage health care professionals and families in learning communities to assure participants have information on how to effectively contribute to the health care system as it relates to deaf or hard of hearing children and their families.
- The EHDI Program is continuing collaborative partnerships with LA School for the Deaf – Parent Pupil Education Program and EarlySteps, to ensure that children who are deaf or hard of hearing have access to the necessary referral(s), care coordination, and pertinent services that will support language acquisition.
- The EHDI Program is addressing the importance of families within the EHDI system by incorporating family members within the learning communities as well as linking newly identified families with Guide by Your Side parent guides.
- The LA EHDI database is now accessible to LA EHDI partner providers such as early intervention programs, Nurse Family Partnership and Parents as Teachers. Database trainings continue to be offered to partner providers and medical home offices who provide hearing re-screenings.
- An active family engagement survey is in draft and when finalized will be offered to families of children birth – 5 years’ old who are Deaf or hard of hearing.

Louisiana Guide By Your Side (GBYS) is the lead family organization for the LA EHDI program. GBYS is a program from Hands & Voices that provides emotional support and unbiased information from trained Parent Guides to families of newly identified children who are deaf or hard of hearing.

- Through the Hands & Voices ASTra (Advocacy, Support and Training) Program, three webinar trainings for families and professionals were held:
 - Assuring Communication Access Using the “Tools for Developing a Communication Plan.”
 - Individualized Education Plan (IFSP) & Transition – What Every Parent Needs to Know
 - Evaluation and Individual Education Plan (IEP) Advocacy
- One of the GBYS Parent Guides presented “Engaging Families and Leaders in a Diverse World” at the National EHDI Conference in Denver.
- Work continues with the National Technical Resource Center for Newborn Hearing Screening and Intervention to improve family engagement, partnership and leadership within the EHDI System.
- Hands & Voices leadership are participating in the HRSA - Family Leadership in Language and Learning Program.

BFH Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program is a no-cost, voluntary program that supports the health and well-being of families with young children. MIECHV implements two evidence-based models, Nurse-Family Partnership (NFP) and Parents as Teachers (PAT). MIECHV pairs families looking for additional support and mentoring with specially trained registered nurses or parent educators who partner with families and provide personal home visits.

NFP and PAT services:

- Health and developmental screenings for children, promoting early identification of developmental delays.
- Assistance with goal setting and life skills development.
- Parenting guidance on a variety of topics.
- Connections to available resources, including early intervention and early childhood special education services.
- Coordinated care and support once families are connected to needed services.

Nurse Family Partnership (NFP):

- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI-eligible first-time moms and families from pregnancy until the child’s second birthday.
- NFP serves all parishes except Caldwell, East Carroll, Madison, Tensas, Union, and West Carroll.

Parents as Teachers (PAT):

- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI-eligible expectant or parenting families from pregnancy until the child enters kindergarten.
- PAT serves Shreveport, Monroe and the 18 surrounding parishes. Now accepting referrals for New Orleans and the 4 surrounding parishes.

Maternal, Infant, and Early Childhood Home Visiting Program SFY 2017 Reach		
Nurse Family Partnership	3,205 families served	33,349 home visits
Parents as Teachers	596 families served	6,112 home visits

For more information about Louisiana MIECHV’s NFP and PAT services, including how to get in touch with a home visitor near you, via the Partners for Health Babies telephone line and website, 1-800-251-BABY and PartnersforHealthyBabies.org.